Dealing with Difficult Discussions at End-of-Life Care

Laura Norwalt

Our Lady of Lake College School of Nursing: Accelerated BSN
Introduction

End-of-life care can best be described as the healthcare involved in the last hours, days, or months of a patient’s life. End-of-life care brings with it many difficult areas of discussion, most importantly the subject of death and dying. Other areas of discussion include palliative care, hospice, legal documentation, withdrawal of life-sustaining treatments, and the upholding of dignity during care (Watson, 2010). As the role of advocate and communicator in the nursing profession, registered nurses have become the major player in end-of-life discussions. The purpose of this review of literature is to examine what barriers occur and what initiatives work during end-of-life care and discussions.

According to Espinosa et al. (2010), “In the United States, approximately 2.5 million people die each year, with 60% of these deaths occurring in hospitals, with half of those deaths involving intensive care units (ICU).” Due to this alarming statistic, a major focal point of end-of-life care focuses on the intensive care registered nurses’ perceptions with such population. While ICU registered nurses demonstrate great technical skills with maintaining end-of-life care, another aspect to consider is focused on the psychological factors that come into play during end-of-life care. These factors include the ICU nurses’ perceptions and barriers to end-of-life discussions.

Other aspects of end-of-life care discussions are identified. One important factor in end-of-life care and discussion is the aspect of incorporation and education of the dying patient’s family members. Another important factor is the use of community nursing staff to begin end-of-life discussions before acute situations occur. In the United States, there is a great movement towards preventative care; as such, end-of-life care and discussions are starting with community nursing. Finally, the last aspect addressed is that in the Western culture, dying and death are
rarely discussed; as such healthcare policies and initiatives relating to end-of-life care are limited.

**Intensive Care Unit Registered Nurses’ Perceptions and Barriers during End-of-Life Care**

To begin this discussion of end-of-life care as related to intensive care unit registered nurses, it is important to note ICU registered nurses’ own perceptions of caring for dying patients. According to McCallum et al. (2013), “providing a peaceful, quiet, and private environment is pivotal in maintaining the dignity of a dying patient and realizing an ideal death.” Within a qualitative study conducted through interviewing five registered nurses working in critical care, McCallum (2013) and researchers examined end-of-life care in a critical care unit. Core themes emerged including ‘the nurse as the protector’, ‘conflict of care’, and ‘peace and quiet’ (McCallum et al., 2013). The first theme emerged due to participants reporting their responsibility to maintain end-of-life patients’ comforts and needs while protecting these patients and their families from unnecessary suffering (McCallum et al., 2013). According to McCallum et al. (2013), ‘conflict of care’ occurs when the participants reported facing moral and ethical dilemmas in relation to medical management which had no effect on the patient’s outcome or resulted in increased patient suffering. In relation to ‘peace and quiet’, McCallum et al. (2013) state, this theme relates to providing a time for obtaining end-of-life wishes and providing for spiritual needs of the patients and their families. While ‘the nurse as the protector’ theme does not register specifically in other articles, the other two themes, ‘conflict of care’ and ‘peace and quiet’, are reflected in a similar study.

In a qualitative study conducted by Vanderspank-Wright et al (2011), six critical care registered nurses were interviewed to explore the involvement of critical care nurses who care for patients during the withdrawal of life-sustaining treatments. The themes emerging from these
interviews include, ‘working in professional angst’ and ‘providing memories’ (Vanderspank-Wright et al., 2011). The first theme ‘working in professional angst’ deeply registers with McCallum et al.’s (2013) theme of ‘conflict of care.’ According to Vanderspank-Wright et al (2011), “conflict arose from when the physicians wanting to continue or discontinue life-sustaining treatment, and the family wanting the converse.” As one can infer when an ICU registered nurse feels that their opinions are not or cannot be heard in regards to end-of-life care, then their experiences are negatively impacted.

The second major theme, ‘providing memories’ from the Vanderspank-Wright et al. (2011), coincides with the finding of ‘peace and quiet’ from McCallum et al.’s (2013) study. According to Vanderspank-Wright et al. (2011), the participants described their role in providing positive interventions to aid in sustaining dignity at end-of-life care. Both studies demonstrate the importance of still engaging the patient and family members in dignity fulfilling life activities during end-of-life care.

Major limitations of both studies are identified. The first issue is the use of a small number for sampling. In McCallum et al. (2013), only five registered nurses were used during interviews while in Vanderspank-Wright et al.’s (2011) research only six critical care nurses were interviewed. A second limitation is the use of only one type of intensive care unit for critical care registered nurse recruitment. Both studies used only nurses on a medical/surgical intensive care unit.

The limitations of the former two studies are addressed by Espinosa et al. (2010) who focused on a qualitative study involving individual interviews of 18 registered ICU nurses working in units varying from medical ICUs, coronary care units, neurological ICUs, and
surgical ICUs. Although this study had a larger sample size and varying types of specialized ICU registered nurses, the results reflect those found in McCallum et al.’s (2013) and Vanderspank-Wright et al.’s (2011) work. The findings identified the theme of “barrier to optimal care” which relates to the other researchers’ themes of ‘conflict of care’ and ‘working in professional angst’ (Espinosa et al., 2010). A new theme of recognition from Espinosa et al.’s (2010) research is “the coping strategies used by the ICU nurses.” The findings include the use of “building trust with the family”, “crying”, “humor”, “talking to others about terminal care”, and “avoiding care for the terminal patients” (Espinosa et al., 2010). While these types of coping strategies may reflect personal preference, they may also reveal another area of concern: the ICU nurse’s ability to handle end-of-life care situations.

While researching ICU nurses’ experiences in end-of-life care, an area of concern is confronting moral distress due to ethical dilemmas. In a quantitative study conducted by Browning (2013), 277 critical care nurses were surveyed through the Moral Distress Scale and the Psychological Empowerment Instrument to evaluate the relationship between moral distress and psychological empowerment in critical care nurses providing end-of-life care. The results concluded that many critical care nurses believe they have some type of empowerment in regards to decision making in end-of-life care but unfortunately do not add to these types of decisions (Browning, 2013). The study’s results describe the top three high-scoring issues for moral distress including “follow family’s wishes to continue life support when not in patient’s best interest”, “follow [physician’s] orders for unnecessary tests”, and “follow family wishes for patient care I don’t agree with” (Browning, 2013). The highest scoring topic for psychological empowerment was “I really care about what I do on my job” (Browning, 2013). The findings from this study conclude that “psychological empowerment was positively correlated with age,
years of experience, collaboration in end-of-life care conferences, and end-of-life care education and were negatively correlated with moral distress frequency” (Browning, 2013). The factors correlating with high psychological empowerment, such as increased education, age, and years of experience, demonstrate what factors influence end-of-life care management by intensive care unit registered nurses.

**Families and End-of-Life Care**

The studies relating to ICU registered nurses’ perceptions during end-of-life care lead to another area of research: the family of the dying patient. While caring for dying patients, it is important to incorporate family members into nursing plans of care. Although the end-of-life care discussions between family and registered nurses literature does not address ICU registered nurses’ specifically; such types of strategies can still be applied in ICU situations.

Family members can include actual relatives, friends, and significant others. As a registered nurse, a great deal of time is spent understanding and caring for not only the patient but their supportive loved ones. Three major tasks are identified to balance this unique multi-person relationship, including building a trusting relationship with the patient and their family, actively listening to family concerns, and acting as an educator. Such tasks are important since patients’ family members and loved ones should be seen as an extension of holistic care for a dying patient (Karlsson et al., 2011).

The first major task, building a trusting relationship, including the end-of-life patient, their family members, and the registered nurse, starts with understanding what barriers hinder this process. According to Clabots (2012), several barriers hinder the ability of registered nurses to begin to initiate end-of-life discussions. The author identifies certain barriers which include
the nurse’s inexperience with death and dying and stress, which affects communication with patients and families (Clabots, 2012). To combat these types of barriers, Clabots (2012) suggest “the nurse should examine personal beliefs, values, and fears about death and dying… and should not project his or her values onto the patient.” Also, the registered nurse should become cultural aware of any family or religious customs (Clabots, 2012). The next step in initiating and maintaining end-of-life discussions with families is through forming a trusting relationship by “offering to answer any questions regarding the plan of care”, utilizing “active listening strategy”, “provide frequent, timely family updates regarding patient status and goals of care”, and “providing anticipatory guidance, support, and frequent follow up to ensure understanding of the plan of care” (Clabots, 2012).

The second task to improve care for end-of-life patients is through actively listening to family members concerns. Family members and loved ones of a patient can provide great insight and detail into wishes and concerns of a patient who is unable to express such issues. In a qualitative study conducted by McEvoy et al. (2012), communication diaries were given to relatives of patients on the Liverpool Care Pathway (LCP). According to McEvoy et al. (2012), the Liverpool Care Pathway is “a way of transferring the best practice of care for dying patients delivered in hospices into other settings including hospitals.” The use of the communication diary was a way to obtain ‘real time’ feedback from relatives about a patient’s plan of care and overall satisfaction. Of the LCP patients and relatives, 59 relatives participated (McEvoy et al., 2012). According to the researchers, “the diary acted as a catalyst to ensure regular communication between nurses and family and carers so that sensitive matters of support were addressed in addition to physical care and symptom control” (McEvoy et al., 2012). This study demonstrates how this constructive tool can be used in many intensive care units or other
healthcare settings to produce positive outcomes for patients and their families dealing with end-of-life care.

While the previous study looks at ‘real time’ data about family members concerns, the following study reflects on retrospective data from ICU patients’ family members about their experiences with the unit. In a descriptive and retrospective qualitative study conducted by Karlsson et al. (2011), 35 family members of critically ill people in a Swedish intensive care unit were surveyed for overall unit satisfaction. The study found that family members’ needs in regards to assurance, information, proximity, and support were met whereas the issue of comfort was less satisfactory (Karlsson et al., 2011). According to Karlsson et al. (2011), “comfort of the relatives’ room is important because the family members spend a great deal of the waiting time there.” Karlsson et al. (2011) and McEvoy et al. (2012) provide examples of how family members concerns can be addressed in respect to end-of-life patients.

The final task associated with the relationship between the end-of-life patient, their respective family members, and the registered nurse is through educating family members so they can respectfully act as fellow advocates. In the United States’ hospital system, the adaptation of a palliative care team has become more commonplace. An area of education needing expansion is the use of palliative measures during end-of-life care. According to Clabots (2012), “the nurse should educate them [family members] regarding the underlying goals of palliative and hospice care as improving the quality of life for the patient and family and reliving suffering during the dying process.” Another area of further education for patients and family members may be on the use of advance directives. According to Clabots (2012), “the nurse should discuss advance directives with all patients and families…the idea behind these
interventions is to prepare and empower the patient and loved ones, providing opportunities to ensure their wishes will be respected at end of life.”

According to Karlsson et al. (2011), another area of educating family members is the registered nurse’s role as translator of a physician’s medical jargon into ‘layman’s’ terms. The authors state, “it is important to emphasize the usefulness of the nurses’ greater participation when the physicians give information, as medical information can be difficult to understand” (Karlsson et al., 2011). Through educating family members, the ICU registered nurse broadens the range of opportunities to explore for end-of-life patients who may not be able to express their own concerns. Consequently, if appropriate, educated family members assert the role of advocate by interceding through with their dying family member’s wishes.

**Community Nursing’s Role in End-of-Life Care**

Since most intensive care unit admissions are a result of acute and life-saving measures, end-of-life care conversations and initiatives need to start with community nursing. Through preparedness and planning of end-of-life care with community nurses, individuals admitted to intensive care units can have in place exact dignity maintaining wishes and avoid unnecessary interventions. Community nurses can commence end-of-life discussions and education.

To begin the discussion of community nurses’ impact on end-of-life care, one must understand the public’s opinion of end-of-life discussions. An article of interest to community nursing highlighted the statistical reality of end-of-life discussions of individuals living in South West Essex of the United Kingdom. The results in this article are from the voluntarily appointed sample of the first 304 people to complete an end-of-life survey as part of local engagement with the general public in South West Essex regarding issues around death and dying (Hickey et al.,
One major statistical finding showed that while 69% of the participants stated feeling secure in discussing death, only 17% implemented plans for a funeral, and only 37% developed a living will (Hickey et al., 2012). Another finding demonstrated that 63% of respondents wished to die at home (Hickey et al., 2012). However, according to the National Council for Palliative Care in 2010, “60% of individuals die in acute hospitals when there is no clinical need to do so” (Hickey et al., 2012). A final remarkable finding is that 78% of participants believe it is the responsibility of a healthcare professional to commence end-of-life discussions (Hickey et al., 2012). This article demonstrates the importance of healthcare professionals, especially registered nurses,

“to find the confidence, competence, courage, and conviction to recognize and seize opportunities that facilitate open, honest, and timely discussions about planning and choice at the end of life, to ensure that dying well is an integral component of living well” (Hickey et al., 2012).

As many individuals express a preference for a ‘good death’ at home, community nurses are helping to make this a possibility. According to Adamson and Cruickshank (2013), certain steps allow a community nurse to facilitate a ‘good death.’ These include “establishing a relationship that includes openness and honesty, conserving dignity, comprehensive assessment, alleviating symptom distress from both a physical and psychological perspective, consistent and timely information giving, open dialogue with patients and families, and anticipation and preparation” (Adamson et al., 2013).

A major way community nurses can begin an end-of-life planning conversation is through education and direct contact discussions. In a qualitative Australian study, the
researchers investigated the implementation process of and experiences of those involved in Advance Care Planning. These individuals included residents, families, and nursing staff. According to the authors, advance care planning is “the process of preparing for likely scenarios near the end of life that usually includes assessment of and dialogue about, a person’s understanding of their medical history and condition, values, preferences and personal and family resources” (Jeong et al., 2010). To research this topic, the authors voluntarily sampled residents, their family members, and nursing staff of three residential care facilities. The researchers adopted a case study approach and collected data through direct observations and interviews with residents, family members, and registered nurses over 6 months (Jeong et al., 2010). The findings of the study conclude that successful implementation of advance care planning is through the involvement of an experienced end-of-life care nurse coordinator to educate registered nurses, quality of education discussion with residents about their planning rather than just making written materials available, and the involvement of multidisciplinary teams, such as palliative care, community nurses, and geriatricians (Jeong et al., 2010).

Matsui (2010) addressed end-of-life care initiatives by conducting a quasi-experimental design in Japan involving a total of 121 older adults, aged 65 years and over, who were split into two groups. The control group only received a handout on end-of-life discussion (Matsui, 2010). The experimental group received “an educational program consisting of a video, a lecture using a handout, and discussion among participants” (Matsui, 2010). At follow-up, “twice as many in the intervention group had discussed end-of-life matters with family members and/or their physician” (Matsui, 2010). These studies illustrate that through education and direct one-on-one discussion adults, especially older adults, can become educated to implement plans for end-of-life care. By starting these educational strategies in the community, such areas of conflict over
end-of-life wishes and concerns can be addressed before entering a hospital or intensive care unit.

Johnston et al. (2012) illustrate a qualitative designed experiment which evaluated the feasibility and acceptability of a Dignity Care Pathway. According to the authors, the Dignity Care Pathway (DCP) is a “therapeutic map, guiding health professionals to structure their care actions against conversing dignity” (Johnston et al., 2012). The DCP has four sections: a Patient Dignity Inventory (which identifies dignity-related distress and the patient’s key concerns) and reflective questions to be used by the patient, and a manual and care actions for the healthcare professional (Johnston et al., 2012). The study sampled 14 community nurses in one health board area of Scotland (Johnston et al., 2012). The findings from the study identified key themes. The first theme is that the majority of the nurses stated that the DCP enabled them to provide more focused care and initiate conversations to start palliative care (Johnston et al., 2012). The impact of the DCP on everyday practice of the community nurses deepened nurse-patient relationships through open communication (Johnston et al., 2012). The overall impact of this study demonstrates that by openingly communicating about dignity-related concerns for end-of-life care, nurses can address such concerns by individualizing end-of-life plans.

As the United States healthcare moves more towards preventative measures, community nursing bridges the gap between initiating these difficult discussions and the actual implementation of end-of-life care. Community nursing helps to shape future outcomes for possible hospitalized patients and upholds each person’s right to die with dignity and respect.
Health Policy Related to End-of-Life Care

In Western society, the topic of death is usually avoided and ignored as a continuum of the life cycle. As such, there is limited end-of-life healthcare policy. To begin this discussion, the distinction between important end-of-life documentation must be addressed. Advance directives are a type of document that allow an individual to outline what type of healthcare he/she would want in an event where he/she is unable to make such decisions. Several types of advance directives exist, including Living Wills and Durable Power of Attorney for Healthcare. Another important type of documentation most commonly seen in a patient’s medical record is Do-Not-Resuscitate orders, which are specific physician orders dictated by the patient stating which lifesaving resuscitation interventions should be implemented in a lifesaving situation.

The first step towards implementation of end-of-life polices began with the United States Patient Self-Determination Act of 1991, which addressed advance directives. According to Watson (2010), this act requires all Medicare or Medicaid funded healthcare facilities and/or providers to address advance directives upon admission and provide education about this type of document.

Another great stride in end-of-life health care policy started with the passing of Patient Order for Life Sustaining Treatment in certain states, including Louisiana as the Louisiana Physician Orders for Scope of Treatment (LaPOST). Whereas advance directives outline a patient’s wishes in legal form, this type of documentation is filled out by one’s physician and relies the patient’s wishes in the form of physician orders. The major topics presented in this document include “cardiopulmonary resuscitation, medical interventions, antibiotic treatment, artificially administered nutrition, other instructions, and summary of goals” (Louisiana Physician Orders for Scope of Treatment, 2013). A major disadvantage presents that while
advance directives allow any adult to complete, LaPOST is limited to only “individuals with life-limiting illness regardless of age” (Louisiana Physical Orders for Scope of Treatment, 2013). Another disadvantage is the possibility of limited respect for this documentation across state lines.

In the 2010 U.S. Patient Protection Affordable Care Act, certain plans to advance end-of-life care were proposed but never implemented. For example, the Act proposed “enabling physicians to be reimbursed for having advance care planning discussions with patients” but was removed from the final draft due to national criticism of the production of “death panels which would ration healthcare in the United States” (Giovanni, 2012).

Moving away from healthcare acts, certain governmental programs, such as Medicare, will feel the strain on increasing end-of-life care needs. According to Nursing Economics, the number of United States adults over the age of 65 years, “by 2050 is predicted to reach 72.2 million” (Giovanni, 2012). This growing demographic will directly impact the Medicare budget in the coming years. According to the current Medicare Payment Advisory Commission, “about a quarter of the total Medicare budget is spent on services for beneficiaries in their last year of life, and 40% of that is in the last 30 days of their life” (Giovanni, 2012).

Another striking statistic in relation to Medicare payment is the huge increase of hospice care. According to the Medicare Payment Advisory Commission, “in 2008 hospice care served over 1 million Medicare beneficiaries, from more than 3,300 providers” (Giovanni, 2012). As life expectancies increase, prevalence of chronic comorbidities rise, and technology advancements propel, more policies need to be adopted to deal with the growing end-of-life issues and budget.
Conclusion

Through the review of literature, as the United States population of older adults increase, there will be more deaths occurring in hospital settings, including ICUs. As such, initiatives need to be implemented to address end-of-life care. Such initiatives need to take into account the barriers that registered nurses, especially ICU registered nurses, face in end-of-life care, such as conflicts both interpersonally and intrapersonally. While there is a great deal of research on how registered nurses in general can begin end-of-life care discussions with family members, there is a gap in literature pertaining specially to ICU registered nurses.
References


